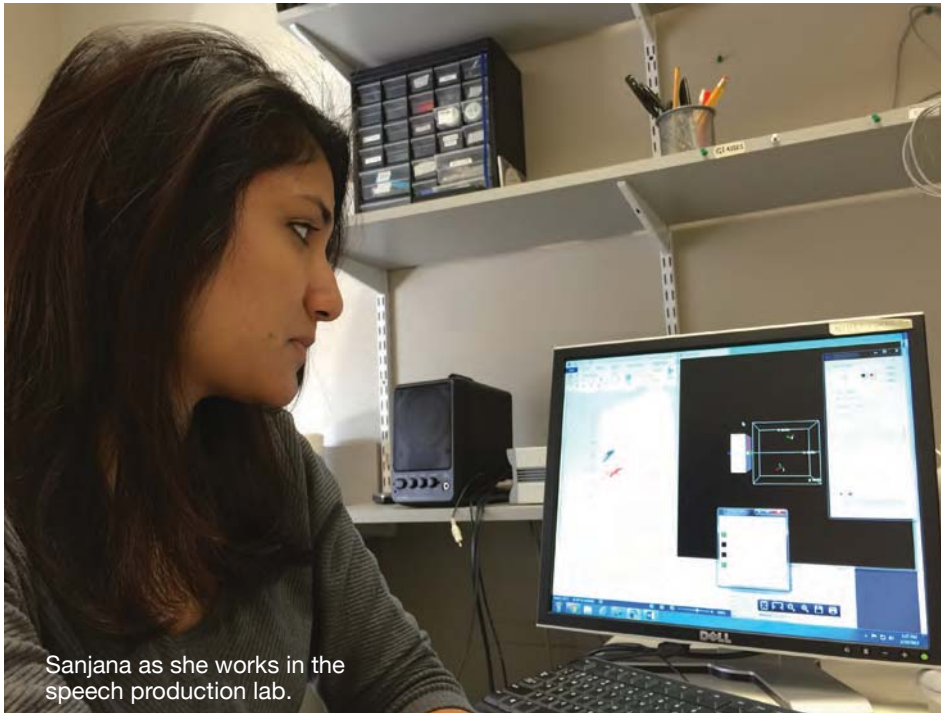


# Brain-Behaviour Relations in Bulbar ALS

By Stefanie Haws, 1T0



Sanjana as she works in the speech production lab.

**THE ALS ICE BUCKET CHALLENGE WENT VIRAL** on social media in the summer of 2014 and in doing so, raised considerable awareness of Amyotrophic Lateral Sclerosis or ALS. While just a fun stunt for some, this challenge raised millions of dollars for ALS-related charities and undeniably increased the public's awareness of this disease. Many chose to participate, and get behind this cause as was evident by the over one million videos posted on social media. Many videos showed people dumping a bucket of ice cold water on their heads, while calling out others to donate to ALS research or complete the challenge. I too participated by dumping a bucket of ice water on my head and donating to support this great cause.

Following this momentum, a movie depicting the life of Dr. Stephen Hawking was released called *The Theory of Everything*. This touching movie tells the story of Dr. Hawking's journey through life with the symptoms of this disease.

With all the focus on ALS in the past year, the S-LP Alumni Association has chosen to profile related research taking place in the Speech-Language Pathology Department at the University of Toronto. I caught up with Sanjana Shellikeri, a PhD student in Dr. Yunusova's Speech Production Lab, and asked about her current ALS research.

### Briefly, what is ALS and its impact on speech?

ALS is the most common degenerative motor neuron disease. It results in muscle weakness, atrophy, and fasciculations, eventually leading to paralysis. Disease effects are also seen in speech musculature, resulting in a loss of communicative abilities. Patients with ALS exhibit smaller and

slower speech movements, leading to a reduction in speaking rate and a loss of speech intelligibility.

### How did you decide to study ALS in Dr. Yunusova's Speech Production Lab?

I met Dr. Yunusova through my mother, who was diagnosed with ALS in 2010. I was a recent undergraduate in Neuroscience and was very interested in contributing to the medical field. Although I didn't have much knowledge in S-LP, I was drawn to the idea of research in a disease that was so close to my heart. After meeting Dr. Yunusova and learning about her work, I knew this line of research would be a great fit for me.

### In 2014, the ALS Ice Bucket Challenge went viral. What were your thoughts about this challenge and did you or someone you know participate in the challenge? What impact do you think the Ice Bucket Challenge had on the public's awareness of ALS?

I remember hearing about the ALS Ice Bucket

Challenge while I was on vacation in Summer 2014. I was extremely optimistic that people would finally be aware of this horrible disease and its consequences. Many people criticized the merit of this Challenge, saying it was just a popularity gimmick among teens and wouldn't directly contribute to the awareness of the disease. However, I strongly disagree. I find that after this Challenge went viral, people became much more familiar with ALS and some people even went further to do their own Google searches on the topic. Even if people didn't donate as per the rules of the Challenge, it was still a wonderful way to get people talking about the disease.

I, myself, didn't participate in the challenge, however a lot of my family and friends from all over the world did. Because the people close to me already knew a little about ALS, they made it a point to donate even if they completed the challenge. Many of my friends and family dedicated the challenge to my mom, who was ecstatic to see the extent to which ALS was in the limelight.

### Can you tell us about your ALS research?

My PhD work focuses on examining the neuroanatomical correlates of Bulbar ALS. Bulbar ALS is a form of ALS that affects the muscles of speech and swallowing function. It has a heterogeneous presentation that is not well characterized. Currently, very little is known about how the structural changes in the brain are associated with the bulbar motor disorder. By establishing this relation, we are hoping to gain a better understanding of the neural degeneration associated with Bulbar ALS. Ultimately, we hope the work contributes to optimizing the identification and monitoring of bulbar disease in a clinical setting. For my project, I will be using neuroimaging techniques (i.e., MRI scans), as well as examining brain specimens post-mortem, of patients with Bulbar ALS and associating the observed structural changes in the brain with speech profiles.

### What is the most exciting thing about working on your current project?

The most exciting thing about working on this project is being exposed to cutting-edge technology and using diverse techniques to investigate research questions. The thrill is also in working towards a real-world impact.

A special thanks to Sanjana for sharing her ALS research with us. We look forward to learning more in the near future!